

The mediating role of duration of disclosure in the relationship between disclosure and psychological wellbeing among children living with HIV in Accra, Ghana

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Abstract

While the relationship between HIV status disclosure and mental health outcomes (i.e. depression and anxiety) among children and adolescents living with HIV is well studied, less is known about the mediating role played by length of HIV disclosure among children living with HIV. Using a purposively selected sample of 134 children living with HIV and their caregivers, this study examined the mediating role of duration of disclosure in the relationship between disclosure of status and psychological wellbeing of children living with HIV. Participants were administered standardised questionnaires that measured psychological wellbeing and length of HIV status disclosure. Hayes Process Model in the Statistical Package for the Social Sciences (SPSS version 23) was used to examine the direct and indirect effects of disclosure of HIV status on psychological wellbeing. The results showed psychological wellbeing was positively associated with both duration of disclosure and disclosure of child's HIV status. Further analysis showed that the duration of disclosure mediated the relationship between disclosure of a child's HIV status and psychological wellbeing. Disclosure of HIV status significantly predicted duration of disclosure and had a direct positive influence on psychological wellbeing. These findings suggest that HIV status disclosure does not adversely affect the wellbeing of children living with HIV as this relationship is mediated by how long the child has been aware of his or her HIV status.

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Introduction

Globally, there are many medical and psychological difficulties that children living with HIV must overcome. These challenges have a substantial negative influence on their quality of life and add to the global disease burden (UNAIDS, 2023). The most challenging of these issues is getting access to antiretroviral drugs, which is made worse by several factors, including stigma, poverty, and the absence of HIV status disclosure (Ebuy et al., 2020; Ravishankar et al., 2022; Shenderovich et al. 2021; UNAIDS, 2023).

To provide the best possible care for children living with HIV, it is imperative that effective HIV status disclosure be made (Gyamfi et al., 2017; Hayfron-Benjamin et al., 2018; Vreeman et al., 2013, 2014). Appropriate HIV status disclosure is accompanied with several benefits including improved psychological well-being, easier access to support networks, better adherence to antiretroviral therapy (ART), and the promotion of honest and healthy dialogue about the children's HIV condition (Prendergast & Evans, 2023; UNAIDS, 2023).

Notwithstanding the acknowledged advantages, research suggests that numerous caregivers in Sub-Saharan Africa, including Ghana, encounter considerable obstacles when it comes to HIV status disclosure (Vreeman et al., 2013). Evidence available in Ghana suggests that the prevalence of HIV disclosure varies from 21% to 33.3% (Amankwah-Poku et al., 2021; Gyamfi et al., 2017; Kallem et al., 2011; Vreeman et al., 2013). This can be attributed to several factors, such as uncertainties about the child's maturity to handle the disclosure of the condition, fear of stigma, and anxiety about possible psychological trauma (Vreeman et al., 2013). This puts caregivers in a challenging dilemma when deciding whether to disclose their children's HIV status. Consequently, this may have a negative impact on their health and result in various psychological problems in the affected children, including poor adherence to ART treatment (Ammon et al., 2018; Toromo et al., 2022; UNAIDS, 2023).

Previous studies within the sub-region have shown that HIV status disclosure can have a major impact on health outcomes, especially psychological wellbeing (Robinson et al. 2023; Vreeman et al., 2013). Additionally, several qualitative studies in Ghana have revealed that while children may initially face emotional and psychological obstacles because of disclosure, these difficulties usually go away over time and the children do not exhibit any long-term symptoms of psychological distress or trauma (Appiah et al., 2021; Atanuriba et al, 2021; Klutsey et al., 2021). This shows that among children living with HIV, the duration of disclosure may mediate the association between disclosure and outcomes related to mental health. The degree to which the duration of disclosure influences these children's psychological wellbeing, however, is not well understood in the Ghanaian setting.

To address this research gap, the present study aimed to examine the mediating effect of disclosure duration on the relationship between HIV status disclosure and psychological wellbeing among children living with HIV. Specifically, the study sought

to: 1) assess the direct impact of HIV status disclosure and the duration of disclosure on psychological wellbeing, and 2) evaluate the indirect effect of HIV status disclosure on psychological well-being through the mediating role of disclosure duration.

Method

Design and participants

A cross-sectional quantitative approach was used to explore the relationships among the variables. One hundred and thirty-four children living with HIV/AIDS and their caregivers (age range of 22–82 years) were purposively and conveniently sampled from four referral hospitals in Accra, Ghana. Participants included in the study met the following inclusion criteria: (1) a child and/or adolescent attending HIV clinic in any of the four major referral hospitals in Accra, Ghana; (2) a caregiver of a child between ages 6 and 15 years living with HIV; and (3) a child or adolescent with HIV who had been on ART for six months or more.

Measures

We measured *HIV status disclosure* using the first four items of the USAID-Academic Model Providing Access to Healthcare (AMPATH) disclosure questionnaire (Vreeman et al., 2014). The AMPATH is a 15-item scale that measures HIV status disclosure, adherence, stigma, and depression among caregivers of children living with HIV/AIDS. If caregivers respond “No” to any of the four questions, they were considered not to have disclosed; however, if caregivers respond “Yes” to all four questions, disclosure is said to have occurred.

Psychological wellbeing was measured using the 15-item Stirling Children’s Wellbeing Scale (Liddle & Carter, 2015). The scale assesses wellbeing in children aged 6-15 years. It has a five-point Likert type response option from 1 (never) to 5 (all of the time). It has two subscales namely “positive emotional state” and “positive outlook,” each of which contains six items and three social desirability items. Total scale scores range from 12 to 60 with higher scores indicating greater wellbeing in children. The 15-item Stirling Children’s Wellbeing Scale has good psychometric properties within the Ghanaian context (e.g., Amankwah-Poku et al., 2021). In this study, the scale yielded an alpha of .86.

Duration of HIV disclosure was measured with a single item that asked caregivers how long it has been since they made disclosure of their child’s HIV status if disclosure was made. The duration of disclosure ranged from 1- 48 months, with an average length of disclosure of 5.46 months (SD = 1.56).

Procedure

Institutional Review Board approval was received from the Ethics Committee for Humanities, University of Ghana (ref: ECH: 008/18-19) and the Ghana Health Service Ethics Committee (ref: GHS/GARHD/007/19). After permission was sought from all four hospitals, children attending ART clinic with their caregivers were approached. The purpose, benefits, and potential risks of the study were explained, and caregivers gave parental consent on behalf of their children, by signing the informed consent form. The first author and a trained assistant administered the questionnaires by reading out the questions and response options for participants to respond appropriately. Each questionnaire was completed within 15-20 minutes. Each child was given tokens of pens, pencils, and erasers. This process of data collection was the same for all four hospitals. The detailed procedure for data collection has been described elsewhere (e.g. Klutsey et al., 2021).

Data analyses

The data was entered in Excel and was then analysed using Statistical Package for the Social Sciences (SPSS version 23). Data was screened for normal distribution and all the variables were within the normality ranges for the indicators of skewness and kurtosis. Pearson r was used to examine the relationships among the study variables and Hayes Process Model in SPSS version 23 was used to examine the direct and indirect effect of disclosure of HIV status on psychological wellbeing. The estimates of the indirect effects were based on running 10,000 bootstrap iterations of computed samples at 95% CI (Hayes, 2017). An indirect effect was significant if the CI did not include zero.

Results

Demographic characteristics of participants

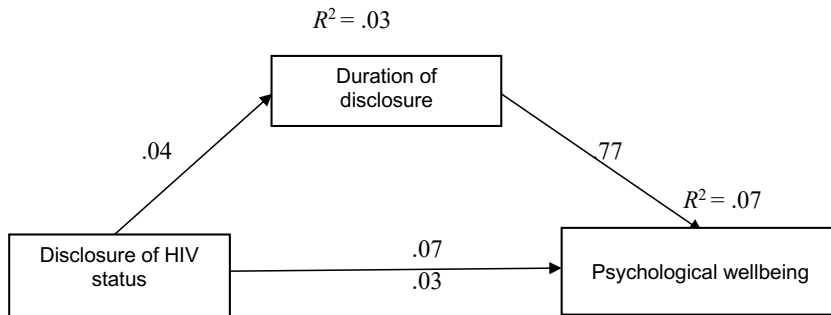
A total of 134 dyads of children with HIV and their caregivers were included in the study. Most of the caregivers were female (102 participants, 76.1%). The average age of the caregivers was 40.80 years ($SD = 9.94$), and 41.0% of them only had a basic or elementary education. Ninety-six (52.2%) of the children sampled were male, and their average age was 9.56 years ($SD = 2.61$). Of the total number of children sampled, 31.3% knew their status as HIV positive, while the majority, 68.7%, did not.

Correlation among variables in the study

The results of correlation analyses showed that the children's psychological wellbeing [$r(134) = .07, p < 0.01$] and the duration of disclosure [$r(134) = .04, p < 0.01$] were positively associated with the disclosure of HIV status respectively. Additionally, there was a positive correlation found between the duration of disclosure and the carers' psychological wellbeing [$r(134) = .77, p < 0.01$].

Mediation results

The results showed that HIV status disclosure had a substantial direct impact on psychological wellbeing even after the length of disclosure was considered as a mediator in the model ($b = .03, p < .001$). Nonetheless, there was a partial mediation as the overall impact of disclosure on psychological wellbeing dropped from ($b = .07$) to ($b = .03$). About 3.3% of the variance in psychological wellbeing was accounted for by the direct structural path model, whereas 6.6% of the variance was explained by the total effect structural path model.



Indirect effect

Disclosure of HIV status → Duration of Disclosure → Psychological wellbeing
 ($b = 0.03, 95\%CI: 0.028, 0.040$)

Figure 1: Structural path of the direct and indirect influences of the relationship between disclosure of HIV status and psychological wellbeing with duration of disclosure as mediator. Both significant and nonsignificant paths are indicated. Unstandardised estimates are reported.

Discussion

The purpose of this study was to investigate the mediating role of the duration of disclosure in the relationship between psychological wellbeing and HIV status disclosure among children living with HIV. Our results showed that 1) children’s psychological wellbeing was positively associated with both duration of disclosure of HIV status and disclosure of HIV status; 2) HIV status disclosure had a substantial direct impact on psychological wellbeing; and 3) Length of disclosure partially mediated the relationship HIV status disclosure and psychological wellbeing.

Our findings showed that the relationship between HIV disclosure and psychological wellbeing was influenced by the duration of disclosure, or the amount of time a child had been told about their HIV status. Thus, children who had known about their HIV status for a longer time showed less psychological and emotional difficulties.

Contrary to the uncertainties held by many caregivers, this finding is consistent with earlier research that suggests disclosure does not adversely affect wellbeing or antiretroviral adherence (Amankwah-Poku et al., 2021; Klutsey et al., 2021; Vreeman et al., 2013). While emotional difficulties upon disclosure are common among children living with HIV, they tend to lessen with time as coping mechanisms are developed to manage the condition (Vreeman et al., 2013).

The findings suggest that children are better equipped to cope with and adjust to their HIV status the longer they are aware of it, which also greatly lessens the unpleasant feelings that come with disclosure. With the help of their family and medical professionals, these children probably acquire coping mechanisms over time. Klutsey et al. (2021), for example, found that while disclosure initially caused negative emotional reactions, such as disengagement, loss of interest in previously enjoyable activities, and depression, these were eventually lessened by assurances from therapists, caregivers, and medical professionals who offered post-disclosure support to address the children's anxieties and concerns about their condition.

This study contributes to the clarification of disparities in the literature about the effects of disclosure on the mental health of children living with HIV. Although this study contributes to knowledge, there are a few limitations that should be taken into consideration when interpreting the results. Causality cannot be inferred from the study's cross-sectional design, which merely permits correlations between predictor factors and outcomes to be assessed. Furthermore, there is a chance of bias because of the use of non-probability sampling techniques. As a result, generalisations should only be made after carefully evaluating the specific context in which this study was conducted.

Conclusions

Contrary to the concerns of many caregivers, the results of this study show that disclosure of HIV status adds to positive psychological wellbeing outcomes for children living with HIV. This mediational study shows that although the initial negative emotional reactions to disclosure are a typical reaction to the diagnosis of chronic illnesses like HIV, these negative reactions eventually lessen. Hence, children living with HIV learn to accept their condition after disclosure is made. As a result, disclosure of HIV status should be encouraged among caregivers of children living with HIV, as this leads to better health outcomes for these young patients.

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